



Disability and Health in  
New York State

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# Women's Special Health Concerns

All women face the threat of developing serious, possibly life-threatening diseases at some time in their lives. Having a disability does not protect one from these health risks. In fact, women who have a physical disability that limits their mobility may even be at increased risk for some medical problems.

All women can lower their risk of developing major health problems by adopting a healthy lifestyle and getting regular check-ups and screening tests to identify illness at an early, treatable stage.

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## Heart Disease

The number one health threat for American women is heart disease. It is estimated that one in every two women will die of heart disease or stroke. There is a popular misconception that heart disease is a man's illness. However, as a woman approaches menopause her risk of heart disease rises with age.

The major risk factors for heart disease include high blood pressure, high blood cholesterol, cigarette smoking and exposure to secondhand smoke, physical inactivity, diabetes, obesity, and poor nutrition. Every woman should receive screening tests to assess her risk for heart disease and be encouraged to make lifestyle changes that can lower her risk.

## Cancer

Women with disabilities are at the same risk as other women for breast, cervical and colorectal cancer. A woman's lifetime risk of breast cancer is one in eight. Lung cancer deaths in women have increased by 450 percent over the past 30 years. Colorectal cancer is the second leading cause of cancer death for both men and women.

The good news is that most cancers can be identified at an early, treatable stage through regular screening tests. All women, regardless of physical limitations or chronic conditions, should have an annual pap test, pelvic exam, and clinical breast exam. Mammograms are recommended for women over age 40 and colorectal screening for those over age 50.

(continued on page 2)

## Inside

this issue

- **Check Your Wellness Score**
- **Health Screening Guidelines for Women**
- **Two Women Share Their Experiences in Finding Sensitive Health Care Providers**
- **State Initiative Increases Access to Cancer Screening**

## Osteoporosis

Osteoporosis occurs more often in women with disabilities. It is a disease in which the bones become thin and weak, often resulting in broken bones. Women who have disabilities that limit their mobility, such as multiple sclerosis, spinal cord injury, cerebral palsy and post polio syndrome, may be at increased risk. They may not be able to participate in weight-bearing exercises that help strengthen bones, and they are more prone to falls. Some medications such as anticonvulsants and steroids also may add to bone thinning.

It is important for women who have a disability that limits mobility to talk with their health care provider about being tested for osteoporosis (a bone density test), developing an exercise plan that is within their range of activities, and ways to increase calcium in the diet.

## Diabetes

Obesity is a major risk factor for diabetes. Diabetes is a special health concern for all women, especially for African American, Hispanic and Native American women. Women with disabilities may be at increased risk for diabetes due to lack of exercise and difficulty in maintaining their ideal weight.

So far there is no cure for diabetes, but it can be controlled through diet, exercise and weight control. A simple urine test to check for sugar should be done as part of an annual checkup. Persons who are at increased risk should have a fasting blood sugar test by age 45 and every three years thereafter.



The "On Target" newsletter is part of People First, a series of health and wellness materials for people with disabilities, their family, friends and health care providers. Health education materials for people with disabilities are also available through the Department of Health's web site at [www.health.state.ny.us](http://www.health.state.ny.us). Just click on the Information for Consumer's icon, and go to the Disability and Health page.

# Health & Wellness Resources

## The National Womens Health Information Center

[www.4woman.gov/wwwd/index.htm](http://www.4woman.gov/wwwd/index.htm)

## Center for Research on Women with Disabilities

[www.bcm.tmc.edu/crowd](http://www.bcm.tmc.edu/crowd)

## Health Promotion for Women with Disabilities

[www.nursing.villanova.edu/WomenWithDisabilities/welcome.htm](http://www.nursing.villanova.edu/WomenWithDisabilities/welcome.htm)

## Breast Health Access for Women with Disabilities

[www.bhawd.org](http://www.bhawd.org)

## American Cancer Society

[www.cancer.org](http://www.cancer.org)

## National Cancer Institute

[www.cancernet.nci.nih.gov](http://www.cancernet.nci.nih.gov)

## American Heart Association

[www.women.americanheart.org](http://www.women.americanheart.org)

## National Osteoporosis Foundation

[www.nof.org](http://www.nof.org)

## National Institutes of Health, Osteoporosis and Related Bone Diseases

[www.osteoporosis.nih.gov](http://www.osteoporosis.nih.gov)

## American Diabetes Association

[www.diabetes.org](http://www.diabetes.org)

# How Well Are You Taking Care of Your Health?

## Check Your Wellness Score!

Getting regular check-ups, screening tests and immunizations are among the most important things you can do for yourself. If you are at risk for health problems, they can be prevented or detected early when treatment is more successful. Answer these questions and add up your points to see how well you score on taking care of your general health.

### Add 5 points for each question you answer YES

	YES	Points
1. Do you have a primary care provider who monitors your general health and recommends needed screening tests?	_____	+5
2. Do you see a gynecologist yearly for a Pap test, breast and pelvic exam?	_____	+5
3. Do you examine your breasts for lumps monthly?	_____	+5
4. If you are over age 40 have you had a mammogram within the past two years?	_____	+5
5. Have you had a blood pressure check in the past two years?	_____	+5
6. If your blood pressure is elevated, are you receiving treatment?	_____	+5
7. Have you had a urine or blood sugar test to check for diabetes?	_____	+5
8. If you are over age 50, have you had a fecal blood test or other test to check for colon cancer?	_____	+5
9. Do you know your cholesterol numbers?	_____	+5
10. Do you check your skin monthly for any change in moles?	_____	+5
11. Have you had a bone density test to check for thinning bones?	_____	+5
12. Do you visit your dentist at least once a year?	_____	+5
13. Have you had your eyes checked for vision changes and diseases?	_____	+5
14. Do you know how to protect yourself from sexually transmitted diseases, including HIV?	_____	+5

### Subtract 5 points for each of these questions you answer YES

15. Do you smoke cigarettes or drink large amounts of alcohol?	_____	- 5
16. Are you more than 20 lbs. over your ideal weight?	_____	- 5

**Total Your Wellness Score** \_\_\_\_\_

### How did you score?

**65 --70 points**

You are taking great care of your health, Keep it up.

**60--50 points**

Ask your doctor if you need additional screening tests?

**Less than 50 points**

You may have an undetected medical problem that could be treated more successfully if identified early.

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# Health Care Challenges Facing Women with Disabilities

*Two women share their experiences and offer advice to help others avoid similar problems*

## **Katinka-**

***“I was so upset following my first attempt to get a pelvic exam that I didn’t seek gynecologic care for five years.” Katinka Neuhof.***



Katinka Neuhof has used crutches for getting around since she was five years old due to her spastic cerebral palsy. But she has never let her disability interfere with accomplishing her life goals.

Born in Montreal, Katinka came to the U.S. for college. She received a liberal arts degree from Sarah Lawrence College and an M.A. in fiction writing from Columbia University. She has written several plays, one which has been produced, and other works of fiction. Katinka has focused her career on helping others with disabilities. She has worked for several agencies that serve people with disabilities, as a case manager, supervisor of a crisis hotline and an educator. She currently serves as a Training & Education Coordinator at the Center for Independence of the Disabled in New York City (CIDNY).

Katinka is a very confident and outspoken person who is very comfortable speaking about the physical limitations caused by her cerebral palsy. But she was so humiliated when she first sought routine gynecologic care that she did not try again for over five years.

### **Tight muscles made pelvic exam impossible**

Based on a recommendation from her primary care physician, she made an appointment with a female gynecologist. But it soon became apparent that the physician and her staff were very uncomfortable with Katinka’s difficulty in getting undressed and getting up on the examination table.

“I tried to tell the doctor that my condition made my muscles very stiff and it could take some time for my limbs to relax,” Katinka reports. “But after they finally got me up on the table and worked my legs into the stirrups, the physician said ‘I can’t do this. Your muscles are too tight.’”

She recommended that I get a sonogram to ‘see what’s going on down there.’”

### **Sonogram experience was the final straw**

But the sonogram proved to be even more humiliating. In preparation for this test, Katinka was directed to drink huge amounts of water. When she

explained that being spastic she could not hold much water, the technician insisted that she try to drink more. Once Katinka was on the table, the technician said she had to leave the room for a few minutes. “I told her that I could not hold the water much longer, but she said ‘Just relax, I will be right back’. She left the room and I lost control. I was totally stressed, soaked in urine, humiliated and shaking.”

### **New gynecologist recommends muscle relaxants**

Five years later, Katinka learned about the Initiative for Women with Disabilities at the Hospital for Joint Diseases in New York City. Even though it was “out of network” so her insurance would not pay, she finally made an appointment. Her new gynecologist was very sensitive to her dilemma. And she had an examination table that could be lowered to make transfer easier.

“The doctor worked for a solid hour to get my body into the right position for the examination. Both the doctor and I were exhausted by that time. And, after all that, the physician could not do a pelvic examination because my muscles were still too tight. The physician suggested that I go to a neurologist to get a prescription for medication that would relax my muscles. “

### **Breast exam leads to breast surgery**

The gynecologist did, however, do a breast examination and found a lump which she aspirated and sent to a laboratory. Luckily it was not cancerous, but Katinka did have to undergo several surgeries for removal of benign tumors. And, with the help of muscle relaxing medication that she takes before an appointment with her gynecologist, the examination is accomplished in less than 20 minutes.

“I know that I am very lucky that I have found a gynecologist with whom I am comfortable,” Katinka says. “And, I want to help other women with disabilities locate health care providers who can meet their special needs.”

## ***Ilona-***

***“I was raised to think doctors are gods, so I was initially embarrassed and intimidated about questioning them or telling them what I need.” Ilona Tylwalk***



Ilona was first diagnosed with Multiple Sclerosis in 1976, but she had symptoms as early as 1971. Her symptoms were not evident to others at first, but for the past 15 years the disease has gradually decreased her mobility. To get around she started out with one cane, then went to two canes and then to a walker. At work she now uses a motorized scooter since her work environment is spread out.

For the past 2 1/2 years, Ilona served as the Director of the Career Center at the Center for Women with Disabilities in Buffalo, New York. Based at Buffalo General Hospital, the Center was developed as a one-



stop health and wellness center for women with chronic disabling conditions. In her role as Director of the Career Center, Ilona helped disabled people get back into the work force, if necessary by identifying a new career choice that they can manage.

### **Vision problems led to MS diagnosis**

When Ilona consulted her eye doctor about unusual vision problems, he correctly referred her to a neurologist for special tests that led to her MS diagnosis.

However, the eye doctor subsequently attributed all of her vision changes to MS. Through the years, he never did the routine eye exam with lenses to check for normal vision changes associated with aging. This is a common problem facing people with disabling diseases. Health care providers may be so focused on the major disease that they may neglect to provide basic, preventive health care.

"I finally went to a new opthamologist who ran the usual eye tests and gave me glasses to correct my normal aging vision changes," Ilona says.

### **A sensitive gynecologist minimizes stress**

Like many other women with mobility limitations, having an annual pelvic examination and Pap test can be difficult. "You would not believe what I have to go through to have a pelvic exam," she says. "Two nurses and the doctor have to help me up on the examination table and get my feet into the stirrups. A nurse then has to hold my legs apart while the doctor is examining my abdomen."

Ilona considers herself very lucky to have a long-term relationship with a very sensitive and caring gynecologist. "Due to the sensitivity of my doctor and his staff, I feel comfortable and am never mortified. But, he is now 70 years old and will be retiring soon, so I will need to choose a new provider," she laments.

### **Problems also arise in the dentist office**

"I need help getting into the dental chair and then I can't lean over to rinse my mouth in the water basin" Ilona says. "My dentist and dental hygienist are also very sensitive to my needs by helping me into the chair and passing me a container to spit into.

"If a health care provider is caring and sympathetic to the needs of patients with disabilities there are ways to make accommodations that don't cost money."

### **Care needed in choosing a health care provider**

Before choosing a new health care provider, Ilona is no longer timid about asking probing questions. "I interview my care providers and the office staff to assess their experience and comfort with treating persons with functional disabilities. I explain my limitations and special needs to the office manager and if possible to the physician or nurse practitioner who will be treating me. That way I am not being unfair to them, and I am not putting myself in a stressful situation."



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# Tips on Choosing a Health Care Provider

*Ilona Tylwalk and Katinka Neuhof agree that finding a health care provider who understands the special needs of persons with disabilities may require some research. Here are their recommendations.*

## Get References

Ask your friends, especially those with similar disabilities, for the names of health care providers with whom they feel comfortable. Or seek advice from support groups or agencies that serve persons with disabilities.

## Research the Web

There is a wealth of health information on the Internet directed to persons with disabilities. The Internet can help you identify health care services you may need and specialized clinics or health care provider groups in your area with experience in serving persons with disabilities.

## Identify Your Special Needs

Before contacting potential providers make a list of your special needs. Don't rely on your memory, write them down for easy reference. For example, do you need:

- an accessible parking space,
- wheelchair accessible entry way, offices and bathrooms,
- help getting undressed or transferring onto a standard examining table,

- help in getting into position for an examination,
- extra time for an appointment to allow for mobility/communication limitations,
- accommodations for vision or hearing impairments.

## Interview Office Staff

Before making an appointment, call the office manager and outline your needs and limitations. Mention that you will probably need a longer than usual appointment.

## Bring Health Information

Keep written records of your health history and bring it with you. You will be asked about the major diseases or illnesses you have had, the nature and onset of symptoms, hospitalizations and surgeries, immunizations, pregnancies, menstruation, allergies, smoking status, and information on medications you take including nutritional supplements, vitamins, herbs and minerals.

## Write Down Your Questions & Concerns

Think about the issues that you want to discuss with your health care provider. It is best to write down your questions and take a list with you to your appointment so you can be sure to cover all of your health questions.

## Take Notes

If possible, take notes during your health care visit. This will help you remember details. Continue asking questions until you are sure you understand your health provider's information and recommendations.

## Bring a Friend

If it would be helpful, bring a friend, relative or attendant to listen and take notes for you. Make sure your health care provider speaks to you rather than to your companion.

# State Initiative Aims to Increase Access to Cancer Screening for Women with Disabilities

Recognizing that some women with disabilities may not be receiving regular screening for breast and cervical cancer, the State Health Department has undertaken a major initiative to help medical providers expand access to these potentially life-saving tests.

There are a number of reasons why women with disabilities may not seek regular gynecologic care. These include limited income, lack of health insurance and transportation problems. But the most frequently cited reasons are inaccessible equipment and lack of health care provider sensitivity to disability.

Women with disabilities that limit their mobility often have difficulty getting onto a standard examination table, as well as difficulty getting into position for a pelvic examination or mammogram. For a woman in a 22-inch wheel chair, it can be extremely difficult to transfer onto a regular 30-inch examination table. For a woman who has a neurological disorder that causes spasms and loss of control of the lower limbs or pain, mounting the table can be impossible

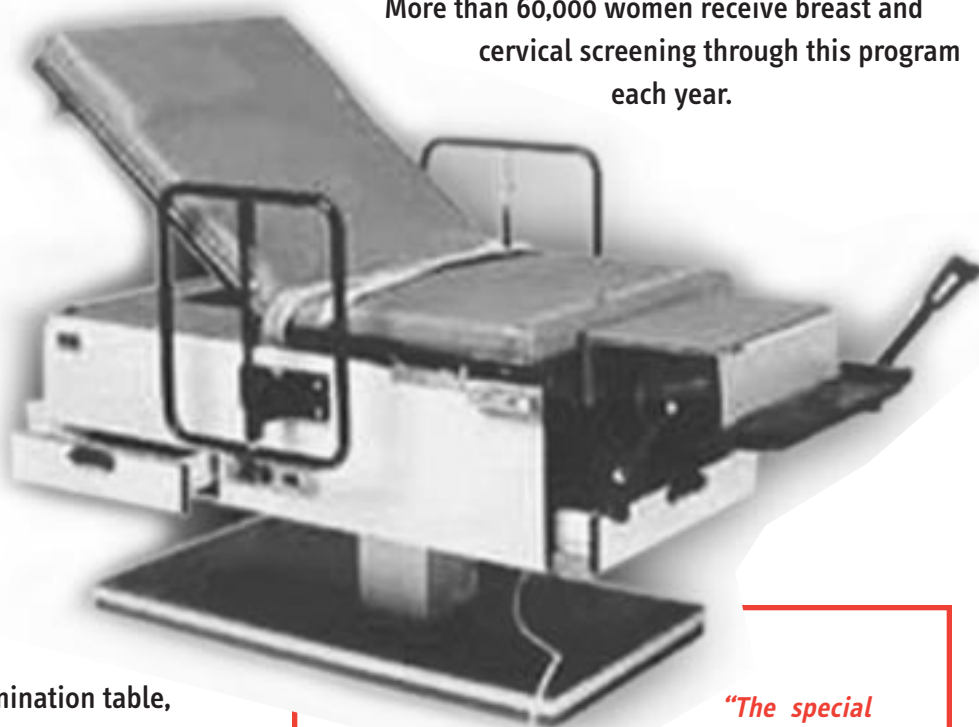
## Accessible Examination Tables

With funding from the Centers for Disease Control and Prevention, the department has purchased and placed 21 special, accessible examination tables in

locations across the State. These tables can be moved up and down to accommodate persons with a range of mobility limitations. Special padded stirrups can be adjusted to help a patient get into position for a pelvic exam.

The new accessible tables have been placed in clinics and physicians' offices that participate in the State's Healthy Women Partnership program. These sites provide free or low cost screening for women ages 40 and older who have no health insurance or whose health insurance does not cover screening services.

More than 60,000 women receive breast and cervical screening through this program each year.



*"The special tables not only help women with disabilities such as MS or cerebral palsy, they also are a boon to pregnant women in the last few weeks of pregnancy," reports Mildred Patnode, Nurse Practitioner at Whitney Young Health Center in Albany. "I have used the table for women in wheelchairs, pregnant women, an elderly woman with severe arthritis, and for an obese woman, all of whom had difficulty lifting themselves onto a regular table."*



## Sensitivity Training

One of the most often-heard complaints from women with disabilities relates to lack of respect and lack of dignity in how they are treated. To address this issue, the Department of Health held six regional training workshops for staff in clinic sites that received tables. More than 175 providers attended the training, ranging from front office staff to nurse practitioners and physicians. The training focused on disability awareness and sensitivity, plus clinical accommodations needed to serve women with disabilities.

## Outreach & Education

Getting the word out to women and health care providers is another major component of the State's program. Clinics that received the new tables are required to conduct ongoing outreach efforts to recruit and refer women with disabilities for cancer screening services. Some clinics now include women with disabilities on their advisory boards, others are working with community based organizations that serve people with disabilities.

"We also are reaching out to neurologists, orthopedists, gynecologists and other health care providers who may have patients with disabilities to let them know that accessible cervical cancer screening is available at Whitney Young Health Center," Ms. Patnode says.

## Service Coordination

The Healthy Women Partnership clinics also strive to assist women with disabilities by helping to arrange transportation if needed, and by arranging multiple, same day appointments to minimize travel time.

# PROVIDERS

**that have received accessible examination tables and staff sensitivity training**

## NORTHERN REGION

Samaritan Medical Health Center, Watertown, NY 315-785-4155  
Alice Hyde Medical Center, Malone, NY ..... 518-483-3000  
Gerald Cahill, M.D., Malone, NY ..... 518-483-8990  
UCP Family Health Care Center, Canton, NY .... 315-386-8191

## WESTERN REGION

The Resource Center, Jamestown, NY ..... 716-661-4782  
Sister's of Charity Hospital, Buffalo, NY ..... 716-862-1624  
Planned Parenthood, Canandaigua, NY ..... 585-396-9270

## CENTRAL REGION

United Medical Associates, Johnson City, NY ... 607-763-8008  
Women's Health Services of Elmira,  
Elmira, NY ..... 607-734-8157  
Syracuse Community Health Center,  
Syracuse, NY ..... 315-476-7921 ext. 580  
Family Health Network of Central New York,  
Cortland, NY ..... 607-753-3798  
Marjorie Tracey, N.D., Auburn, NY ..... 315-255-1668  
St. James Mercy Health System, Hornell, NY .... 607-324-8147

## HUDSON VALLEY/CAPITAL REGION

Whitney Young Health Center,  
Albany, NY ..... 518-465-4771 ext. 230  
Family Planning Clinic at Public Health,  
Catskill, NY ..... 518-943-5679  
Planned Parenthood of Mid-Hudson Valley,  
Poughkeepsie and Beacon, NY ..... 845-471-1540

## NEW YORK CITY

Callen-Lorde Community Health Center,  
New York, NY ..... 212-271-7207  
Morris Heights Health Center,  
Bronx, NY ..... 718-716-4400 ext. 2338  
St. Vincent Catholic Medical Centers,  
Jamaica, NY ..... 718-558-9308  
Elmhurst Hospital Center, Elmhurst, NY ..... 718-334-5443

Although some providers already have accessible examination tables, such as hospitals and large clinics, this initiative improved access by increasing the number of accessible tables available. The providers listed above have newly acquired accessible examination tables. Contact the provider closest to you if you could benefit from this feature.

# Sensitivity Plus!

## Etiquette for Communicating with People with Disabilities

The following recommendations were developed by CIDNY, the Center for Independence of the Disabled in New York, Inc. This material was presented by CIDNY at sensitivity training workshops provided for health care personnel by the State Health Department.

- ① 1. When talking with a person with a disability, look directly at the person rather than at the person's companion, assistant or sign language interpreter.
- ① 2. When introduced to a person with a disability it is appropriate to offer to shake hands. People with limited hand use or who use a prosthesis can usually shake hands. Shaking hands with the left hand is an acceptable greeting.
- ① 3. When meeting a person who is visually impaired, always identify yourself and others who may be with you. When conversing in a group, remember to address the person to whom you are speaking by name. Always announce when you are leaving the group or conversation.
- ① 4. If you offer assistance, wait until the offer of help is accepted. Then listen to or ask for instructions.
- ① 5. Treat adults as adults. Address people who have disabilities by their first names only when extending the same familiarity to all others. Never patronize people who use wheelchairs by patting them on the head or shoulder.
- ① 6. Never lean on or hang on to a person's wheelchair. The chair is not a piece of furniture. It is part of the personal space of the person who uses it.
- ① 7. Be patient and listen attentively when you are talking with a person who has difficulty speaking. Wait for that person to finish, rather than correcting or speaking for him or her. If necessary, ask short questions that require short answers, a nod or shake of the head. Never pretend to understand if you are having difficulty doing so. Instead, repeat what you have understood and allow the person to respond. The response will clue you in and guide your understanding.
- ① 8. When speaking with a person who uses a wheelchair or a person who uses crutches, place yourself at eye level in front of the person to facilitate the conversation.
- ① 9. To get the attention of a person who is deaf or hard of hearing, place yourself in his/her line of sight, make eye contact and make whatever gesture is natural for you to indicate that you wish to communicate. Look directly at the person and speak in a normal tone of voice (not louder). If the person wishes to communicate by writing or in some other way, he or she will let you know. If the person lip reads, avoid eating, covering your mouth or turning away while speaking. Keep alert to cues that the person can understand you (nodding head, eye contact, etc.). Never tap the person from behind unless it's an emergency (i.e., physical danger).
- ① 10. Don't be afraid to ask questions when you are unsure of what to do. Persons with disabilities are the experts on their own needs and are used to questions. Relax and be yourself.

*These recommendations were developed by CIDNY, the Center for Independence of the Disabled in New York, Inc., (212-674-2300 / kneuhof@cidny.org)*

# Put Your Focus on Wellness & Prevention



## Health Screening Guidelines for Women

With a wellness focus you can protect your health and improve your quality of life. By taking a proactive role in getting regular screening examinations, you can prevent problems before they occur. Prevention is the key to living long and living well.

Screening Tests	Age	Recommendation
Full checkup	18-49 years 50 & older	every 1-3 years every year
Blood pressure test	18 & older	every two years
Blood cholesterol test	20 & older	first test at age 20 then every 5 years
Urine test for diabetes	18 & older	every year
Blood sugar test	45 & older	every three years
Breast exam	18 & older	monthly self exam yearly by health care provider
Mammogram	35-39 years 40-49 years 50 & older	baseline test every 1-2 years every year
Pap smear	18 & older	every 1-3 years
Fecal blood test	50 & older	yearly
Colonoscopy	50 & older	every 5 - 10 years
Sigmoidoscopy	50 & older	every 5 years
Bone density test	menopause	women with mobility limitations may need Screening earlier
STD tests	sexually active	yearly or at exposure to an infected or questionable partner
Eye exam	20-39 40 & older	initial exam, every 2-4 years
Dental exam	age 2 & older	1-2 times yearly
Skin cancer exam	18 & older	monthly self exam yearly by health care provider

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“On Target” is also available on audio cassette or in large print.  
For a copy, contact the Disability and Health Program at  
(518) 474-2018 or [www.health.state.ny.us](http://www.health.state.ny.us) (Disability and Health Link)



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